

Socio-Economic Challenges in Childhood Cancer Care in a Low-Middle-Income Country: The Children's Hospital Lahore Experience

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ABSTRACT

Background: Each year, it is estimated that over 200 000 children and adolescents are diagnosed with cancer, and 80% of these reside in low-middle-income countries, with 90% mortality. There are enormous psychosocial needs of these patients, families, and care-givers, which are primarily affected by the communities' social, economic, cultural, and religious factors.

Aim: To elucidate the significant psychosocial and socio-economic issues faced by the caregivers of children suffering from different types of cancer at the Children's Hospital Lahore.

Study design: Prospective cohort study

Place and duration of study: Department of Paediatric Hematology and Oncology, Children's Hospital Lahore Pakistan from 1st January 2018 to 30th June 2018

Methodology: Two hundred family members/caregivers of the patients were enrolled with ages ranging from <1 to 15 years (43% <5 years and 57% >5years old).

Results: Male to female ratio was 1.2:1. 52% belonged to hematological malignancies and 48% from solid tumor groups. Most of these children had malnutrition with anemia (81% with Hb <10g%) and small weight forage in 63% cases at presentation. 80% of families had more than three children, with the youngest child being less than five years in 75%. 95% of families relied on public transport, with 65% of them traveling 100-500Km with 2-10 hours duration to reach the primary treatment center. 80% had a monthly income of less than USD150. 68% of these families had to borrow money for trip to hospital (p-Value=0.003), and 58% took a loan for treatment course.

Conclusion: The significant socio-economic challenges faced by these families and caregivers included large family size with low incomes increasing their financial difficulties, logistic burden like traveling long distances to access health care, and parental employment and family dynamics disruptions.

Keywords: Socioeconomic Challenges, Childhood Cancer, Low-Middle-Income Countries

INTRODUCTION

Each year it is estimated that more than 200 000 children and adolescents are diagnosed with cancer, and 80% of these reside in LMIC, with over 80% mortality. Poor outcomes of these children with cancer in LMIC are caused by advanced stage at presentation, abandonment of treatment with baseline malnutrition, inadequate supportive and palliative and curative care services.¹ There are enormous psychosocial needs of these patients, families, and caregivers primarily affected by the communities' social, economic, cultural, and religious factors. There is an extensive range of interventions from self-care to professional care to tackle these needs. In LMIC, longitudinal studies of psychosocial experiences should be done to develop interventions that are suitable in local culture using the available information technology².

PPO research describes the psychosocial risks for these children with cancer and their families during and after treatment and the need for evidence-based guidelines and comprehensive interventions to reduce this emotional distress and support them fully. However, the provision of

these psychosocial services differs markedly in different pediatric oncology centers throughout the globe³. Psycho-oncology defines the psychosocial sequelae of cancer, its treatment, and the need for integrated care of these patients, including the physical, mental, social wellbeing, and family dynamics. This has a marked impact not only on the patients but also the family member's quality of life⁴. For a family, the extent of the cancer crisis in a child is explained by these features of interrupted family dynamics and relationships, uncertain job status and compromised family economy, unpredictable future, dwindling coping and adaptive skills, the emotional trauma of pain, and fear etc.⁵ These parents have colossal stress due to relocation to new cities for their children's cancer treatment with adjustment issues and worries about their other children back home in LMIC⁶. The stress of caring for a child with cancer can cause an increased risk of mild to severe psychological symptoms in parents and siblings. Therefore, the need for psychosocial support for these children and their families for better functioning has grown and has become an integral part of pediatric care over the past five decades⁷.

The research related to distress associated with living with cancer and psychosocial care needs is lacking in

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developing countries. There are enormous psychosocial needs of these patients, families, and caregivers, which are primarily affected by the communities' social, economic, cultural, and religious factors. There is an extensive range of interventions from self-care to professional care to tackle these needs. In LMIC, longitudinal studies of psychosocial experiences should be done to develop interventions that are suitable in local culture using the available information technology⁸. This study evaluated the extent of psychosocial challenges faced by these families in an LMIC like Pakistan in a public sector hospital with resource-limited settings. Very few studies are done locally to emphasize the need for psychosocial screening and the whole family's wellbeing during childhood cancer treatment.

MATERIALS AND METHODS

This prospective cohort study was conducted at Department of Paediatric Hematology and Oncology, Children's Hospital Lahore Pakistan from 1st January 2018 to 30th June 2018. A total of 200 family members/ care givers of children (age <15 years) with a diagnosis of cancer (hematological as well as solid tumors) and on planned chemotherapy were interviewed after obtaining consent using a questionnaire. The family's respondents were selected using a random sampling method. The data were analyzed using the SPSS16.

RESULTS

There were 60% males and 40% females with ages ranging from 1-15 years. Eighty six (43%) were less than five years old, and 114(57%) were between 5 to-15 years old. 63% of these cancer patients were small for age at the time of diagnosis, and only 27% were appropriate for age, along with low hemoglobin of less than10g/dl in 81% of cases and more than 10g/dl in only 19% of cases (Table 1).

Table 1: Baseline nutritional status

Variables	No.	%
Gender		
Male	120	60.0
Female	80	40.0
Age (years)		
<5	86	43.0
>5	114	57.0
Haemoglobin		
<10g%	162	81.0
>10g%	38	19.0
Weight		
Small for age	126	53.0
Appropriate for age	54	27.0

The significant challenges faced by these families were the large family size of more than five members with the financial burden, logistics, family integrity, and sibling education, as shown in table 2 and 3. 80% of families had more than three children, and 75% families had the youngest child being less than five years adding strain onto taking care of their sick child. These families had tremendous logistics challenges with long travel distances and the use of inefficient public transport. In addition to that, they had to borrow money for multiple visits to Primary Treatment Center (The Children's Hospital Lahore) p-

value=0.003 and took loans to complete therapy for different expenses and utilities in addition to the cost of therapy which is provided free of cost from the Ministry of Health p-value=0.008. The study brought out that the cancer patient suffered due to these challenges and the siblings who remained at the mercy of other people for their daily and educational needs.

Table 2: Logistics and Financial Challenges

Variables	No.	%
Transport		
Public	190	95.0
Personal	10	5.0
Distance to primary treatment centre (Km)		
< 200	70	35.0
200-500	112	56.0
>500	18	9.0
Monthly income (USD)		
<150	160	80.0
>150	40	20.0
Borrowing money for hospital visits		
Yes	136	68.0
No	64	32.0
Loans taken		
Yes	116	58.0
No	84	42.0

Table 3: Family Integrity and effect on Siblings Education

Siblings being taken care at home	No.	%
Grandparents	108	54.0
Parents	30	15.0
Elder siblings	22	11.0
Relatives	16	8.0
Self care/alone	24	12.0
Siblings education affected		
Yes	102	51.0
No	98	49.0

DISCUSSION

The study demonstrated the psychosocial socio-economic challenges faced in LMIC in a public sector hospital ranging from large family size, domestic household hardships, dynamic family disruptions, and ineffective counselling of families, all leading to grim outcome eventually. The majority of these children had baseline malnutrition which decreased their ability to cope with intensive therapy protocols resulting in more complications and poor survival.⁹ LMIC have younger populations and, therefore, more children with cancer than high-income countries and a high mortality rate, with infections being a significant risk factor in poor countries¹⁰.

In this study, 95% of families were using public transport to the Children's Hospital Lahore for their multiple visits for therapy and later for follow-up and long-distance travelling of over 200 Km from their hometowns to the hospital, increasing their financial burden tremendously. The findings of our study are in line with a study done in the USA by Zheng et al¹¹ in 2018 that showed that for non-emergency medical transportation to the clinic, only 9% of families used public transportation, 12% required rides from others, and 5% being unsure of their transport to the hospital for appointments.

Our study was done in Pakistan, ranked 154th globally for nominal GDP per capita in 2019 with a 220 million population. A study was done by Ribeiro et al¹² in 2008 for baseline paediatric oncological services in 10 LMIC showed that postulated 5-Year survival was directly proportional to the per capita GDP (p value= 0.008) and annual governments healthcare expenditure per capita (p value=0.0001). The majority of these families had a monthly income of less than 150 USD, with the need to borrow money from relations in 68% and get bank loans in 58% to meet the additional expenses during lengthy treatment despite free treatment provided in the hospital. Another study done in the USA by Smith et al¹³ in 2019 showed that adolescents and young adults having cancer face enormous financial challenges affecting their care and outcome when they lose their health insurance.

Due to the strong connection between poverty and child health outcomes, several paediatric oncology associations recommend routine clinical poverty screening of these children. One study done in the USA showed 44% of families had some form of household material hardship ranging from some monetary problem to a situation where it was difficult to meet basic family needs of food, housing, and utilities, and 39% described that they could be offered financial help from friends or colleagues if needed.¹⁰ Poverty is associated with adverse health outcomes in paediatric primary care and a negative prognostic criterion in childhood cancer. Another study done in the USA by Bona et al¹⁴ showed 20% of families were reported low-income, and 25% of families lost over 40% of annual household income due to treatment-related work disruptions.

Our study showed that siblings had to stay without parents in 85% of cases during the prolonged treatment phase, helped by grandparents to look after them in 54%, looked after by relatives in 8%, and looked after by no one in 12% of cases. One study done by Wiener et al¹⁵ in the USA in 2012 showed that siblings felt lonely as their parents spend more time in the hospital, and consequently, they have to spend more time with friends or extended family during treatment duration, disrupting their everyday life routine with multiple psychological problems over time. Our study showed inadequate knowledge of the disease among parents (52%) due to overcrowding and lack of ample time for health professionals to counsel the families adequately, as shown by one study done in Indonesia s two paediatric oncology hospitals by Aziza et al¹⁶ in 2019 that parents need to know more information about cancer in addition to having anxiety and depression.

CONCLUSION

The major psychosocial, socio-economic challenges faced by these families were large family size with less income increasing their financial burden, logistic burden like travelling long distances to access health care, family dynamics disruptions leading to increased abandonment,

morbidity and mortality in childhood cancer care in an LMIC like Pakistan.

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